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ORIGINAL ARTICLE

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Traumatic brain injury patients' family members' evaluations of the social support provided by healthcare professionals in acute care hospitals

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Abstract

Aims and objectives: The study aimed to examine traumatic brain injury (TBI) patient family members' (FMs) experiences of the support they received from healthcare professionals in acute care hospitals.

Background: The length of hospitalisation following TBI is constantly decreasing, and patients may return home with several problems. FMs care for the patients at home although they may not be prepared for the patient's medical needs or financial burden of the illness. The burden which some FMs experience can impair patient care and rehabilitation outcomes. Therefore, FMs require support during acute phases of TBI treatment.

Design: A structured questionnaire was sent to 216 TBI patients FMs. The response rate was 47% (n = 102).

Methods: A structured questionnaire—based on a systematic literature review and a previous questionnaire on TBI patient FMs' perceptions of support—was developed and used in the data collection. The questionnaire included 46 statements and 11 background questions. Data were collected via an electronic questionnaire. The STROBE checklist was followed in reporting the study.

Results: A factor analysis identified five factors that describe the guidance of TBI patient FMs: guidance of TBI patients' symptoms and survival; benefits of guidance; needs-based guidance; guidance for use of services; and guidance methods. Most of the FMs (51%–88%) felt that they had not received enough guidance from healthcare professionals in acute care hospitals across all five aspects of support.

Conclusions: The content of guidance should be developed, and healthcare staff should be trained to consider a FM's starting point when providing guidance. A calm environment, proper timing, sufficient information in different forms and professional healthcare staff were found to be key factors to comprehensive guidance. Involving

FMs in the discharge process and rehabilitation of their loved ones both supports the abilities of caregivers and promotes the outcome of the patient's rehabilitation.

Relevance to clinical practice: This study provides varied information on the need for social support of TBI patients FMs in the early stages of treatment from the FMs' perspective. This research adopted the FM's perspective to identify various areas of social support that need to be developed so that the FMs of TBI patients receive enough support during the early stages of TBI treatment.

KEYWORDS

family members, guidance, social support, traumatic brain injury

1 | INTRODUCTION

The length of hospitalisation following traumatic brain injury (TBI) is constantly decreasing (Lehan, Arango-Lasprilla, Reyes, & Quijano, 2012), and TBI patients may return home with several problems (Manskow et al., 2018). Family members (FMs) continue to care for the patients at home even though they are rarely prepared to manage the TBI patient's medical needs or the financial burden of the illness (Manskow et al., 2018). A TBI often has life-changing consequences and, as such, can significantly affect the patient's ability to live independently. FMs are often the primary caregivers following discharge, which is why brain injury also significantly changes the lives of a patient's loved ones (Doser & Norup, 2016).

Traumatic brain injury can cause a wide range of problems for the patient, which generally makes caregiving challenging. As a result, TBI patient FMs have experienced psychological anxiety, stress and depression (Manskow et al., 2018), social isolation, financial problems, difficulties accepting their new role (Doser & Norup, 2016; Manskow et al., 2017) and impaired quality of life (Norup et al., 2015). Furthermore, some FMs have reported excessive drug or alcohol use during their time as a caregiver (Leibach et al., 2014; Stevens et al., 2013). Rehabilitation is a long process for both the patient and the family. A patient with more severe cognitive problems will require extensive help from FMs with most aspects of everyday life. The various problems associated with TBI can significantly burden FMs, which, in turn, may impair patient care, rehabilitation and the rehabilitation outcomes. Therefore, FMs require support during the acute phase of treatment (Manskow et al., 2018). There is a lack of research about how TBI patient FMs perceive social support during the acute phases of TBI treatment. This study focuses on acute care, meaning the period when a traumatic brain injury (TBI) patient is hospitalized for the first time after the accident (from the emergency department to the hospital ward).

What does this paper contribute to the wider global clinical community?

- Provides insight into TBI patient family members' experiences of the social support they received from healthcare professionals at the beginning of TBI treatment and highlights areas which need to be developed.
- Hospitals should develop the content of guidance and standardise how guidance is provided at early stages of TBI treatment to reduce stress and anxiety among TBI patient family members, and thus, prevent potential mental health problems.
- We will use the results of this study in a project from the Traumatic Brain Injury Association of Finland ("Supporting Traumatic Brain Injury Family Members") to develop a model for how TBI patient family members can be empowered in neurosurgical and neurological wards.

1.1 | Background

According to Finfgeld-Connett (2005), social support consists of emotional and practical support. Emotional support includes empathy, presence and listening, among others, while practical support comprises the provision of various services and financial support. Emotional and practical supports also include the FMs' support needs, social support networks and an environment that adapts to social support needs. Coco, Tossavainen, Jääskeläinen, and Turunen (2011) studied social support from the TBI patient FM perspective, and identified the following three components: informative; emotional; and practical. The concepts of informative support and guidance are closely related, both requiring an active and an interactive function (Kääriäinen & Kyngäs, 2010). Social support is a process between people where interaction plays a key role. Therefore, one of the most important features of social support is the provision of guidance and advice, which in turn include informative, persuasive and valid information and facts (Finfgeld-Connett, 2005). According to Kaakinen, Patala-Pudas, Kyngäs, and Kääriäinen (2012), guidance should include social and emotional support. Good quality guidance requires appropriate guidance materials, guidance methods and sufficient time, as well as competent healthcare professionals (Kaakinen, Kääriäinen, & Kyngäs, 2012). Other studies have found

that nurses should provide TBI patients' FMs with enough information about TBI and related issues (Stevens et al., 2013), yet also seek to motivate and encourage the FMs (Arango-Lasprilla et al., 2010) to utilise their own personal networks and resources (Finfgeld-Connett, 2005; Stevens et al., 2013). Emotional and practical support (Tramonti et al., 2015) and guidance (Driscoll, 2010) can help relieve and reduce the anxiety and stress experienced by FMs, as well as prevent burnout.

FMs assist TBI patient in many different areas and may therefore experience significant burden. According to previous studies, FMs' main needs were related to concrete knowledge of the patient's problems, the possibility to discuss the care with healthcare professionals and receiving truthful answers about the patient's care (Leibach et al., 2014; Norup et al., 2015). In addition, TBI patient FMs require informal and formal support (Lehan et al., 2012; Leibach et al., 2014), which includes emotional support from the healthcare professionals, as well as support for integration into the community (Tramonti et al., 2015). In another study, FMs reported needing more information about arrangements at home as well as different counselling and training services, for example, physiotherapy, professional guidance and mental health rehabilitation (Leibach et al., 2014). Furthermore, Norup et al. (2015) reported that FMs want the opportunity to participate as much as possible during the early stages of TBI treatment (Norup et al., 2015).

To provide the best possible level of social support, healthcare professionals must be adept at identifying FM needs and determining whether FMs are willing to receive support (Arango-Lasprilla et al., 2010; Norup et al., 2015). The need for support is affected by the FM's ability to live independently and the expectations of others (Finfgeld-Connett, 2005). By understanding FM needs, healthcare professionals can help reduce the chance of treatment failure at home due to stress and anxiety. This can also reduce the unnecessary use of healthcare services and subsequent hospitalisation (Lehan et al., 2012). In addition to providing FMs with sufficient information about TBI and its treatment, healthcare professionals can support FMs by guiding them in how to find additional support resources (Shanta & Eliason, 2014; Sigurdardottir et al., 2015; Wåhlin, 2017). The provided information and guidance must be multidimensional to meet the expectations and needs of TBI patient FMs. Positive interaction between healthcare professionals and TBI patient FMs can contribute to feelings of empowerment (Coco et al., 2011; Sigurdardottir et al., 2015), and thus reduce the sense of burden experienced by loved ones (Sakanashi & Fujita, 2017). When discussing empowerment, it is important to state that this is not something that can be transferred from one person to another, but rather supported by those around the FM (Hawks, 1992; Sakanashi & Fujita, 2017, Sigurdardottir et al., 2015, Yeh, Ma, Huang, Hsueh, & Chiang, 2016).

1.2 | Aim

The purpose of this study was to examine traumatic brain injury patients' FMs' views of the social support they received from healthcare professionals in the acute care hospitals. Additionally, the objective was to develop a questionnaire to measure the social support received by TBI FMs. The specific research questions were the following:

1. What types of social support do TBI patient FMs receive at the beginning of TBI treatment?
2. Which background variables are related to the social support experienced by FMs?

2 | METHODS

This study employed a structured questionnaire that was developed based on a systematic literature search and a previous questionnaire on TBI patient FM support (Coco, 2013). The questionnaire consisted of 46 statements and 11 FMs' background questions. A five-point Likert scale (5 = strongly agree, 4 = agree, 3 = neither agree nor disagree, 2 = disagree, 1 = strongly disagree) was used to gauge the views and experiences of support among FMs of TBI patients (Polit & Beck, 2017). The structure, clarity, coherence and comprehensibility of the questionnaire were evaluated by a team of experts (an author of the study, M.Sc. students, an Executive Director of the Traumatic Brain Injury Association, a professor at the University and a postdoctoral researcher) before the questionnaire was distributed to participants. The questionnaire was also evaluated and piloted by two TBI patient FMs before the actual research. Some necessary changes were made to the questionnaire based on evaluations from the expert panel and the FM pilot test.

The data were collected in August 2017 via an electronic questionnaire. The participants (N = 216) were both members of the Traumatic Brain Injury Association of Finland and TBI patient FMs. The Executive Director of the Traumatic Brain Injury Association sent the TBI patient FMs a link to the questionnaire by email. The participants were informed about the study via a cover letter, which outlined the objectives of the study and clarified the voluntary and anonymous nature of participation (Grove, Burns, & Gray, 2013). Reporting of this research adheres to STROBE checklist (see Supplementary File 1) for cross-sectional studies.

2.1 | Data analysis

The data were analysed using SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, NY, USA).

Factor analysis was conducted to identify factors related to TBI patient FMs' needs for social support. The analysis employed the principal axis factoring method with direct oblimin rotation to achieve a factor solution in which each variable meaningfully loaded clearly only onto one factor. The analysis yielded a five factor solutions: (F1) guidance on TBI patients' symptoms and survival (14 items e.g. "I received enough information and guidance on the problems that a brain injury can cause…"); (F2) the benefits

of guidance (8 items e.g. "Guidance increased my knowledge of traumatic brain injury"); (F3) needs-based guidance (11 items e.g. "Healthcare professionals sought to establish a confidential relationship"); (F4) guidance on use of services (5 items e.g. "I got enough information about social benefits for caregivers"); and (F5) guidance methods (8 items e.g. "Sufficient time was reserved for guidance"). This factor solution explained 75.5% of the total variance and variance explained by each factor F1 20.6%, F2 16%, F3 14.8%, F4 14.3%, F5 9.8%. The loadings for individual variables u-m;7▯uol▯▯▯o▯▯▯7▯b|▯1ollm-▯b|b;v▯u-mbm▯uol▯ 0.556 to 0.902.

Mean sum variables, each representing one of the identified five factors, were then created. The sum variables showed good internal consistency based on Cronbach's alpha values, which ranged between 0.913 and 0.942. This also indicates that the scale is reliable. Kolmogorov–Smirnov and Sharipo–Wilk tests were used to test data distribution, and the results of both revealed that the variables did not follow normal distribution. Relationships between the background variables and sum variables were examined using the Mann–Whitney *U* test for two independent variables and the Kruskal–Wallis test for several independent variables (Polit & Beck, 2017).

Due to a relatively small amount of participants, the Likert scale was compressed into three levels: agree; neither agree nor disagree; and disagree when presenting frequencies and percentages (Polit & Beck, 2017).

2.2 | Ethics

This study received approval from the study association as the study participants were members of the association. The FMs were informed about the study, its voluntary nature and the anonymity of their participation through a cover letter. Anonymity was ensured by recording the material and reporting the research results in such a way that it was not possible to recognise individual participants. Responding to the questionnaire was considered as conscious consent to participate in the study. The study material was collected in a total sample to ensure equality of participation in the study (Polit & Beck, 2017).

3 | RESULTS

3.1 | Background information about the TBI patient FMs

The questionnaire was answered by 102 TBI patient FMs, reflecting a response rate of 47%. Most of the participants were women (*n* = 95). FM age ranged from 26 to 76 years, with an average age of 53 years. Many (50%) of the FMs had completed a higher education degree. About half of the FMs were parents of TBI patients, while the other half were spouses. The majority of patients' accidents had occurred after the year 2010 and almost all of the TBI patients had been treated in the intensive care unit. Most of the TBI patients had been hospitalized for more than 2 weeks. The length of ward treatment varied from 1 day to 2 weeks. About half of the FMs had met a physiotherapist and a social worker during the treatment period. Only a minority of the FMs had met a peer group, even though most of the FMs had expressed this as their main wish at the beginning of the treatment (Table 1).

3.2 | Family member evaluations of the social support provided by healthcare professionals

Family member evaluations of the adequacy of information and guidance provided by healthcare professionals during the early stages of treatment are presented in Table 2. The results show that the percentage of TBI patient FMs who agreed with statements regarding the guidance and informative support provided by healthcare professionals varied from 3% to 44%, while the percentage of the FMs who disagreed with these same statements varied from 51% to 88%.

3.3 | Guidance on TBI patients' symptoms and survival

Family member assessments of whether the information and guidance they received regarding TBI symptoms were adequate showed a clear trend, namely, a majority of FMs found the guidance to be bm-7;t-|;▯u;▯-m▯▯=▯=▯;▯▯▯

TABLE 1 Background information on TBI patient family members (FMs) (*n* = 102)

Background information	n (%)
Gender	
Female	95 (93)
Male	7 (7)
Age group (years)	
Under 40	11 (11)
40–49	26 (26)
50–59	34 (33)
60 or over	31 (30)
Education	
Primary school	17 (17)
Vocational education	34 (33)
Higher education degree	51 (50)
Relationship to patient	
Parent(s)	44 (43)
Spouse	42 (41)
Other loved ones	16 (16)
Care environment (*n* = 102)	
Intensive care unit	79 (77)
Hospital ward	16 (16)
Emergency department	7 (7)
Length of treatment period (*n* = 102)	
1–4 days	15 (15)
5–8 days	25 (25)
9–14 days	20 (20)
More than 2 weeks	39 (40)
Year of the treatment period (*n* = 95)	
Before 2000	12 (13)
2000–2009	19 (20)
2010 or after	62 (67)
Did you meet a social worker during the treatment period?	
Yes	39 (38)
No	63 (62)
Would you have liked to meet a social worker? (*n* = 62)	29 (47)
Did you meet a psychiatric nurse during treatment period?	
Yes	12 (12)
No	89 (88)
Would you have liked to meet a psychiatric nurse? (*n* = 57)	35 (61)
Did you meet a physiotherapist during treatment period?	
Yes	42 (41)
No	60 (59)
Would you have liked to meet a physiotherapist? (*n* = 77)	15 (20)
Did you meet a peer support group during treatment period?	
Yes	4 (4)
No	98 (96)
Would you have liked to meet a peer support group? (*n* = 56)	36 (69)

clear majority of the FMs disagreed with the following statements: healthcare professionals encouraged me to take part in discharge planning (76%); healthcare professionals were interested in the well-being of the children and family (71%); and healthcare professionals gave me the opportunity to talk about my feelings (68%). In addition, the majority of FMs estimated that they had received insufficient guidance on the use of assistive devices (60%), on preparing for the future (86%), on identifying and responding to the needs of loved ones needs (84%), and on finding balance between work, leisure and rest (84%). FMs felt that they received the least guidance on using digital services (3%) and how to control their own behaviour (4%). Less than half of the FMs agreed with statements about how healthcare professionals sought to establish confidential relationships with them (38%) or were interested in their coping (29%).

3.6 | Guidance on use of services

A clear majority of TBI patient FMs perceived a lack of guidance and information regarding family-related services. Only one-quarter (23%) of FMs agreed that they had received sufficient information about patient's rehabilitation services while a clear majority (64%) disagreed with the statement. Furthermore, most of the FMs felt inadequately informed about opportunities to get social and psychological (74%) or peer support (80%). Only 21% of FMs reported getting enough information about how a brain injury will affect family activities.

3.7 | Guidance methods

The results concerning FMs' perceptions of the guidance methods used by healthcare professionals showed that only 25% of the participants felt that healthcare professionals consider the starting point of the patient and family when providing guidance, with 65% of respondents disagreeing with this statement. The majority of TBI patient FMs disagreed with statements that sufficient time was reserved for guidance (78%), the guidance was organized in a quiet place (62%), and the discussions with healthcare professionals included practical guidance (72%). Furthermore, the FMs were left wanting more oral and written information, with only 20% and 14% reporting to have received enough oral and written information, respectively. A worrying result is that a significant proportion of FMs felt that the guidance did not consider the needs of the patient and FMs (72%). Only a small minority of the participating FMs reported experiencing group guidance (6%).

3.8 | Relationships between background variables and FM experiences of social support

The relationships between background variables and FM experiences of social support (described by the five mean sum variables) revealed

TABLE 2 TBI patient family members' perceptions of the guidance and informative support they were provided by healthcare professionals (*N* = 102)

Guidance on TBI patients' symptoms and survival **Mean 2.45** SD **± 1.38 Alpha 0.942**	**Family member evaluations of received support % (f)**		
	Agree	**Neither agree nor disagree**	**Disagree**
I received enough information and guidance on the problems that a brain injury can cause…			
Memory and concentration problems	34% (34)	8% (8)	58% (57)
Slowness in processing different kinds of information	30% (30)	6% (6)	64% (63)
Aggression	28% (28)	12% (12)	60% (59)
Depression	26% (26)	11% (11)	63% (62)
Stress disorders	24% (23)	10% (10)	66% (66)
Hearing problems	19% (18)	10% (10)	71% (68)
A feeling of dependence	17% (16)	16% (15)	67% (68)
I got enough information and guidance that a brain injury may impair the patient's…			
Ability to take care of themselves	44% (44)	5% (5)	51% (51)
Ability to survive independently	42% (42)	6% (6)	52% (52)
Functional outcome	39% (39)	7% (7)	54% (54)
Ability to cope with work	38% (37)	8% (8)	54% (52)
Interaction	35% (35)	7% (7)	58% (58)
Ability to manage free time	31% (31)	9% (9)	60% (60)
Financial performance	28% (28)	7% (7)	65% (65)
The benefits of guidance **Mean 1.93** SD **± 1.12 Alpha 0.926**	**Family member evaluations of received support % (f)**		
	Agree	**Neither agree nor disagree**	**Disagree**
Guidance increased my knowledge of traumatic brain injury	23% (21)	9% (8)	68% (64)
Guidance increased my skills in treating a brain injury patient	21% (19)	12% (11)	67% (61)
Guidance increased my understanding of a traumatic brain injury patient	21% (19)	12% (11)	67% (62)
Guidance improved the survival of the brain injury patient	17% (16)	15% (14)	68% (62)
Guidance reduced the anxiety and stress towards caregiving	11% (10)	9% (8)	80% (72)
Guidance increased my readiness to provide care	11% (10)	10% (9)	79% (69)
Guidance promoted the family's return to daily life	10% (9)	13% (12)	77% (71)
Guidance increased communication between family members	9% (8)	15% (14)	76% (70)
Needs-based guidance **Mean 1.85** SD **± 1.14 Alpha 0.921**	**Family member evaluations of received support % (f)**		
	Agree	**Neither agree nor disagree**	**Disagree**
Healthcare professionals…			
Sought to establish a confidential relationship	38% (37)	7% (7)	55% (54)
Were interested in my coping	29% (28)	3% (3)	68% (67)
Demonstrated how to use an assistive device that could help the patient manage everyday life	20% (16)	20% (16)	60% (48)
Gave me the opportunity to talk about my feelings	19% (18)	13% (12)	68% (65)
Were interested in the well-being of the children and family	19% (16)	10% (8)	71% (59)
Encouraged me to take part in the discharge planning	18% (17)	6% (6)	76% (73)
Guided me to prepare for the future	10% (10)	4% (4)	86% (83)
Guided me on how to recognise and respond to the needs of my loved one	9% (9)	7% (7)	84% (81)
Guided me on how to find a balance between work, leisure and rest	8% (8)	8% (8)	84% (81)
Guided me on how to control my own behaviour	4% (4)	8% (8)	88% (84)

(Continues)

TABLE 2 (Continued)

Needs-based guidance Mean 1.85 SD ± 1.14 Alpha 0.921	Family member evaluations of received support % (f)		
	Agree	Neither agree nor disagree	Disagree
Showed me how to use digital services	3% (3)	11% (10)	86% (75)
Guidance on use of services **Mean 1.88** SD **± 1.04 Alpha 0.918**	**Family member evaluations of received support % (f)**		
	Agree	**Neither agree nor disagree**	**Disagree**
I got enough information about…			
Patient rehabilitation services	23% (23)	13% (13)	64% (64)
How a brain injury will affect family activities	21% (21)	6% (6)	73% (73)
Access to social and psychological support	18% (18)	8% (8)	74% (74)
Opportunities for family peer support	10% (10)	10% (10)	80% (79)
Social benefits for caregivers	4% (4)	12% (12)	84% (84)
Guidance methods **Mean 1.94** SD **± 1.11 Alpha 0.913**	**Family member evaluations of received support % (f)**		
	Agree	**Neither agree nor disagree**	**Disagree**
Healthcare professionals considered the starting point of the patient and family	25% (23)	10% (9)	65% (61)
Guidance was organized in a quiet place	23% (21)	15% (14)	62% (57)
Guidance provided sufficient oral information	20% (18)	10% (9)	70% (67)
I got practical guidance on how to help the TBI patient (e.g. washing, eating, using the restroom)	18% (15)	10% (8)	72% (60)
Healthcare professionals took into account the needs of the patient and their family members	17% (16)	11% (10)	72% (67)
Sufficient time was reserved for guidance	15% (14)	13% (12)	72% (67)
Guidance provided sufficient written information	14% (13)	14% (13)	72% (67)
Group guidance was used	6% (5)	10% (9)	84% (76)

that the care unit significantly influenced all the studied aspects of social support. In this way, TBI patient FMs had better experiences of guidance of TBI patients' symptoms and survival (p = .010), use of services (p = .013), methods used in guidance (p = .034), needs-based guidance (p = .001) and benefits of guidance (p = .011) at the intensive care unit than at hospital wards. Furthermore, meeting with multiprofessional healthcare workers showed a significantly positive relationship with the following aspects of social support: guidance of TBI patients' symptoms and survival (social worker p = .005, physiotherapist p = .001), use of services (social worker p = .019, physiotherapist p = .001), methods used in guidance (social worker p = .045, physiotherapist p = .000), FM needs-based guidance(social worker p = .003, psychiatric nurse p = .020, physiotherapist p = .000) and benefits of guidance (social worker p = .044, physiotherapist p = .001). The TBI patient's treatment year also showed statistically significant differences in FM experiences of social support during the early stages of TBI treatment. The FMs of patients who had received treatment between 2000 and 2009 reported more positive experiences of social support than the FMs of patients who had received treatment since 2010 in regards to TBI patients' symptoms and survival (p = .034) and benefits of guidance (p = .012).

4 | DISCUSSION

In this study, the FMs were quite unanimous in that they had received inadequate information and guidance on the symptoms and effects of brain injury. More specifically, the FMs would have liked more information on how brain injury will affect the patient's daily life and family functioning. Similar results have previously been reported, for example, a study by Arango-Lasprilla et al. (2010) identified emotional and instrumental needs, as well as a desire for more support from healthcare professionals, among TBI patient FMs. Other research found giving instructions and advice to be the most important feature of social support (Finfgeld-Connett, 2005), while Norup et al. (2015) reported that FMs were most interested in concrete knowledge of the patient's problems. It seems as though there is a gap between healthcare professionals' and FMs' perceptions of provided support, as Coco et al. (2013) found that, in general, healthcare professionals feel as though they provided patients' FMs with enough information on the treatment of brain injuries.

Most FMs felt that the healthcare professionals did not sufficiently consider the starting point of the patient and family. It is understandable that all patients and their FMs have different baseline

situations and, as such, not all people may need separate guidance. However, other FMs may be anxious and stressed about their new caregiver role and, for this reason, it is vital that healthcare professionals can address their specific needs and worries when giving advice. Healthcare professionals should be able to recognise whether the FMs are willing to receive guidance (Arango-Lasprilla et al., 2010; Finfgeld-Connett, 2005; Norup et al., 2015) to avoid later treatment failure at home (Lehan et al., 2012). According to Roscigno (2016), healthcare professionals in acute care are good at recognising FMs' trauma and grief responses, but do not always recognise FMs' activity in terms of being more involved in the treatment by sharing important information about their loved one and family. The FMs felt that discussing their feelings with healthcare professionals would have relieved their sense of fear, anxiety and shock. Similar results of the benefits of discussion and sharing feelings have been reported by Leibach et al. (2014). However, the results from this study differ from what was presented by Coco, Tossavainen, Jääskeläinen, & Turunen (2012), that is, healthcare professional estimated that they provide TBI patient FMs with individualized discussions and treat then with respect.

More than half of the FMs disagreed with statements that they were adequately informed about rehabilitation services, the possibility of peer support and social benefits for caregivers. This may be explained by healthcare professionals not having complete knowledge about the services available to caregivers, in particular, social services. In addition, FMs need support from healthcare professionals to handle financial matters; this point is especially relevant when financial matters were previously handled by the injured person. According to FMs, financial problems increased their sense of anxiety and burden. This result agrees with what was reported earlier by Leibach et al. (2014), that is, providing FMs with adequate information about social services can reduce the financial problems associated with brain injury and the anxiety they cause. FMs' needs present at different stages of TBI patient care (Falk, 2013): therefore getting sufficient information, guidance and support from healthcare professionals, and talking about different care options for a TBI patient, is important to FMs. FMs do not necessarily themselves understand the need to seek and search guidance and alternative treatment facilities from the healthcare staff due to their own state of shock. Providing more information about different treatment options, along with positive interaction between healthcare professionals (Sakanashi & Fujita, 2017), can reduce their sense of burden and experience of being alone, and increase their integration and social participation (Hanks, Rapport, Wertheimer, & Koviak, 2012; Kreutzer, Stejskal, Godwin, Godwin, & Arango-Lasprilla, 2010).

The FMs also felt that the guidance was not organized in a quiet place, and that insufficient time was reserved for the guidance. The FMs felt that they were unable to absorb all of the provided information under such stressful and urgent circumstances, a problem which was exacerbated when the information was not provided in writing. Previous research has shown that a calm environment (Fleming, Kuipers, Foster, Smith, & Doig, 2009) reserving ample time (Leibach et al., 2014) and providing written information (Marcus, 2014) helps the family absorb and understand the information better.

The FMs evaluated the guidance better if they had met a social worker, a psychiatric nurse and/or a physiotherapist during the treatment period. An interesting result of the research was that peer group meetings were very rarely part of the guidance even though the FMs had often specified that they would like to meet with a peer group in their development proposals. An explanation for this finding may be that peer support groups are a fairly new support service and, as such, have not yet been fully integrated into the patient care and hospital services.

5 | STRENGTHS AND LIMITATIONS OF THE RESEARCH

The validity of the questionnaire was confirmed by operationalising the theoretical concepts into measurable variables by applying relevant literature. In addition, literature searches were made with an informaticians' help. The theoretical structure and the internal consistency of the questionnaire were evaluated by factor analysis and by Cronbach's alphas showing the good internal consistency. (Grove et al., 2013.) However, some limitations should be noted. A new questionnaire was developed for this study because no previous questionnaire on the researched subject was identified from previous literature. The questionnaire was pre-tested by only two TBI patient FMs (although it underwent scrutinisation by an expert panel), which may have left some area of the research phenomenon unmeasured. Moreover, it must be taken into consideration that, for example, additional FM focus group interviews could have provided more depth to the responses.

One third (33%) of the respondents reported that their loved one had experienced the around 7 years ago or even earlier, which may limit the reliability of the findings. It is possible that respondents do not remember exactly what kind of social support and guidance they received several years ago from the healthcare staff. However, FMs' views did not differ significantly in terms of the social support and guidance received from healthcare staff, regardless of how long ago the accident occurred. The response rate for the study (47%) was considered substantially enough to reliably provide information about how TBI patient FMs perceive social support at the beginning of TBI treatment. However, as the analysed data were collected from Finnish FMs, the results may not be generalisable to other countries or cultures (Grove et al., 2013).

6 | CONCLUSIONS

This study has shown that FMs need individualized guidance that considers their specific needs. Involving FMs in the discharge process and rehabilitation of their loved ones both support the abilities of caregivers and promote the outcome of the patient's rehabilitation.

Healthcare professionals encounter TBI patients and their FMs in very different situations, who have different needs. TBI patients' situations can be very difficult, which may present challenges for healthcare professionals to implement holistic and family-centred approaches in the care of the patients and their families. This requires that nursing staff have sufficient readiness and multidimensional practical competences to recognise the FMs' needs individually and to provide the support they need. Therefore, every healthcare staff member should have received enough education (as well as periodic additional education) to ensure that they can identify FM needs and then choose the appropriate guidance method. In the future, it would be important to develop the implementation of guidance, especially from the perspective of the FMs well-being, for example, by extending and developing guidance to the FMs' home environment. Additionally, leaders should recognise the individual skills and knowledge of their healthcare staff, and support them in sharing guidance knowledge to other team members.

Family members can be supported in their caregiving role by either developing effective guidance methods, improving the current quality of guidance or increasing knowledge level and skills among FMs. The aim in the development of the guidance and support methods is best achieved in a co-operation between the FMs and healthcare professionals. Multiprofessional co-operation and digital services should be proactively used to support the guidance. Healthcare staff can enhance FMs' understanding of TBI and its consequences by guiding FMs in how to search for new information. The healthcare organisation is responsible for the provision of effective early stage guidance, and can ensure that patients' FMs are provided with high-quality information by implementing modern, evidence-based nursing practices and offering their staff additional education.

The FMs of patients who had been hospitalized for 9–14 days scored the guidance they received better than the FMs of patients who had stayed at the hospital for 1–4 days. This could be explained by the fact that FMs and healthcare professionals have more time to interact with each other if the patient is hospitalized for a longer period of time. This could translate to more guidance and better information on brain injury issues. This result suggests that certain parts of healthcare organisations, especially those with a stressful, hectic environment, limited resources and short stays (e.g. emergency room), should proactively develop early stage guidance. FMs do not necessarily have the strength and understanding to seek guidance, which means that healthcare professionals shoulder this responsibility.

Family members of patients who had received treatment between 2000 and 2009 stated that they had received more information and guidance about services than the FMs of patients who had been treated since 2010. However, it is important to note that this finding only concerned *TBI patients' symptoms and survival* and *the benefits of guidance*, while other areas of guidance were estimated to have been better implemented after the year 2010 and worse before the year 2000. An explanation for this finding may be that healthcare professionals' education has impacted the positive development of guidance. From an organisational perspective, this could also mean that nursing practices have developed noticeably since the start of the twenty-first century. Nevertheless, some areas of social support need to be developed further, as a clear majority of the participating FMs were dissatisfied with various aspects of the guidance they received. Many of the FMs identified peer group meetings as an important factor in coping. This is clearly one area of social support that healthcare organisations must develop further in the coming years. Future research should focus on the perspective of nursing staff and work to clarify which factors prevent the implementation of social support. Additionally, the links between effective guidance and a hospital's organisational factors should be studied.

7 | RELEVANCE TO CLINICAL PRACTICE

Family members can be supported in their caregiving role by either developing effective guidance methods, improving the current quality of guidance or increasing knowledge levels and skills among FMs.

- The timing and environment in which guidance is provided, access to sufficient information from various sources, a calm environment and professional nursing staff have all been identified as key factors of successful comprehensive guidance.
- Peer group meetings are an area of social support that healthcare organisations must develop further.
- Early stage guidance of TBI patients' FMs requires further development, especially in the emergency department.
- The content of guidance should be developed, and healthcare staff should be educated to consider the FM's starting point when offering guidance.
- Multiprofessional co-operation and digital services should be proactively used to support the guidance.
- Nursing department leaders play a key role in changing and developing nursing practices.
- A rushed clinical environment and inadequate knowledge among healthcare staff are internal organisational problems that can be influenced by nursing unit managers.
- The healthcare organisation is responsible for the provision of effective early stage guidance and can ensure that patients' FMs are provided with high-quality information by implementing modern, evidence-based nursing practices and offering their staff additional education.

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CONFLICT OF INTEREST

The authors declare no conflicts of interests.

AUTHOR CONTRIBUTION

JC was involved in all aspects of this research, designed and conceived the study, and was responsible for completion and submission of the manuscript. HT and KC were involved in the design of the questionnaire, the analysis of the data and the interpretation of the study results. HTS was involved in the interpretation of data and in writing the manuscript. All authors contributed to the writing of the manuscript and accepted the final manuscript.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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